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TITLE: Long-Term Follow-Up Model for Detection of Potential Toxicities Following Perinatal Exposures

AUTHORS: Shively, N (Florida Family AIDS Network); Emmanuel, P (University of South Florida, College of Medicine, Department of Pediatrics)

ISSUE: The utilization of antiretrovirals in pregnant women has become commonplace since the issuance of the results of ACTG 076 and the USPHS guidelines. Pregnant women are not only receiving zidovudine during their pregnancy, but combination drug therapies as well. There exists a lack of long-term information on the potential toxic effects of these medications on the growth and development of the HIV- and antiretroviral-exposed children.

SETTING: University of South Florida (USF), College of Medicine, Department of Pediatrics; Early Intervention Consortium (EIC) of Hillsborough County with United Cerebral Palsy (UCP) of Tampa Bay as the lead agency.

PROJECT: The Florida Family AIDS Network (FFAN), a Title IV program administered through the USF College of Public Health, has initiated several activities in the pediatric immunology clinic. (1) USF Pediatrics developed the Long-Term Follow-Up (LTFU) study which includes annual histories and physical examinations for all antiretroviral-exposed infants until the age of 21 years; (2) initial development evaluations of all antiretroviral-exposed infants at one year of age, unless otherwise prescribed by one of the pediatricians on staff, and then annually; (3) hearing screenings at each visit for all antiretroviral-exposed infants; and (4) an ongoing database tracking all the parameters of the examinations and evaluations listed above so as to identify any potential toxic effects on the growth and development of the child until (and through) adolescence. FFAN solicited the involvement of UCP of Tampa Bay, serving as the lead agency for the EIC, to partner with the pediatric immunology clinic in providing the developmental evaluations and the necessary developmental and rehabilitative services recommended. A community-based alliance has been established to assist in maintaining the family in the system of care as well as providing multiple points of access to care.

RESULTS: To date, 70 antiretroviral-exposed infants and children have received an additional developmental evaluation and/or supplemental developmental rehabilitative services. There have been 29 antiretroviral-exposed children enrolled in EIC. There are multiple community partners involved in the various components of the LTFU model and a variety of funding streams (local, state, federal) utilized to cover the costs of the array of services provided.

LESSONS LEARNED: The experience of FFAN's LTFU program through USF Pediatrics thus far suggests that the need for long-term follow-up of HIV-exposed children exposed to antiretrovirals in utero is necessary. In order to be able to support and conduct such a model it is imperative to have wide spread, community-based participation and funding from multiple sources at the local, state and federal level. The interactive partnering of medical providers and community-based organizations is a key component in the success of the long-term follow-up program.

PRESENTER CONTACT INFORMATION

Name: Patricia J. Emmanuel, M.D.

Address: 17 Davis Blvd., Suite 200
Tampa, FL 33606

Telephone: (813) 272-2743

Fax: (813) 272-3358

E-mail: pemmanue@com1.med.usf.edu